Partnering with Patients on the Autism Spectrum

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Financial Disclosures

I have no financial relationships to disclose.

Objectives

- Provide practical guidance for healthcare providers (HCPs) and allied healthcare professionals to successfully engage children with ASD and their families.
- Highlight best practices for early ASD detection and treatment.
- Encourage maximal inclusion of those with ASD in healthcare encounters.
- Promote awareness of the challenges and unmet healthcare needs of this vulnerable population.
- Explore multi-disciplinary community action.

Autism Spectrum Disorder (ASD)

- 1 in 68 school-aged children - IDENTIFIED.
- Causes significant communication
  - social and
  - behavioral challenges.
- Learning, cognitive, and problem-solving abilities of people with ASD vary widely.

ASD Information

- ASD diagnosis now comprises:
  - autistic disorder,
  - pervasive developmental disorder not otherwise specified (PDD-NOS), and
  - Asperger syndrome.
- Lack of self-perceived HCP competency reported.
- Improvements needed to effectively identify and care for children with ASD.

ASD Signs and Symptoms

- Lack interest in others and difficultly relating to them (absence of joint attention).
- Avoidance of eye contact.
- Failure to point at objects to convey interest or to look at objects when others point at them.
- Preference for solitude.
- Inability to empathize.
- Difficulty conveying personal needs and desires.
- Exhibition of unusual reactions to sights, smells, tastes, textures, or sounds.
- Inability to engage in pretend play.
- Preference not to be touched or only on ones own terms.
- Appear unaware when others speak to them and/or hyper attentive to other sounds.
- Failure to initiate play/interactions.
- Repeat or echo words or phrases, or repeat words or phrases in place of normal language (scripting).
- Display restricted, repetitive actions.
- Difficultly navigating routine changes.
- Loss of skills previously attained (regression).

First Signs

- Changes in emerging behaviors, and structural brain changes have been documented in infants by 6 months of age.
- The ASD "diagnostic odyssey" from initial concern to diagnosis is complicated for children and families.
- Long waitlists increase anxiety and valuable intervention time is lost.

Early Intervention is Key

- ASD can be reliably diagnosed by age 2
  - greater opportunities for intervention to support improvements in function and quality of life.
- Effective interventions at earliest possible age
  - Modifies early experiences,
  - Alters cognitive organization to enhance learning.

Early Intervention Developments

- The vast majority (87 percent)
  - Prior to age 3 had developmental concerns noted in their educational or medical records.
- Less than half the children identified with ASD (43 percent)
  - received comprehensive developmental evaluations by age 3.

Voice for the Voiceless

- https://www.youtube.com/watch?v=1qPFAT4p8Lc

Best Practice Next Steps

- Approach concerns rather than avoid!
- ASD is evolving from a lifelong condition with a very poor prognosis to one in which, significant neuroplasticity gains may be realized.
- Decades of research reveal early intervention services may greatly improve a child's development. To ensure a child reaches his/her full potential, it is critical to secure help immediately.
- Advances in genetics and neuro-imaging offer detection vehicles prior to the syndrome becoming fully manifest.

Impact on Healthcare Provision

- **Gaining Attention:**
  - Influence of healthcare contexts and practices engendering manifestations of behavior and socio-communicative challenges
- **Further research is needed to discern effects of socio-communicative and sensory impairments evident in ASD on healthcare provision.**

A Different World

"It is too easy to get frustrated and be dismissive of some of the difficult autistic children, because they are running around the office more, they may be more destructive, it's hard, very hard to do an exam, you don't know how far you are getting through." …

A Different World

"They have a logic going on in their own brain, interpreting the world in a different way, speaking a different language. So the burden is upon me to understand them as much as it is for them to understand our world. It is not about decreased intelligence, it's a different world." – Dr. Taketa

Enacting Competence

- HCPs interactions with typically developing children with a chronic illness has been linked to parent adherence to prescribed treatments and care satisfaction.
- Parents of children with ASD highly value rapport build with HCPs, with emphasis on visit greetings.

Practical Tips

- Call the child by name
- Position yourself to their eye-level
- Engage the child whether you perceive they are unable or able to participate.
- Foster opportunities for the child with ASD to safely practice navigation of societal demands.

Make Appointments Meaningful

- Arrange an informal trip prior to an actual trip (graduated exposure).
- Take pictures of key facility areas, equipment, and healthcare staff.
- Allow the person with ASD to watch a family member undergoing a similar exam.
- Inform staff of patient condition and encourage patience.

Make Appointments Meaningful

- The first or last appointment of the day is ideal.
- Ask about health care history and prior health care exposures.
- Allow caregivers to stay in the room if possible.
- Allow extra time to accommodate any additional patient needs when possible.

Interaction

- Explain what you will be doing prior in initiation of any exam/procedure.
- Show the person the equipment and let them touch it.
- Provide a picture illustrating what will happen.
- Avoid extra language – Less words is better!
- Enlist caregiver/supporter help when possible as needed.

Communication

- Speak in short sentences with clear, simple language.
- Use concrete, literal, language.
- Set up a contingency (First, then ____)
- Ask for specific information.
- Give direct requests.
- Avoid figures of speech, metaphors, idioms, words with double meaning or irony.
- Gestures, body language and facial expressions may not be understood.
- Directly assess understanding.

Modes of Communication

- Facilitate information exchange in a manner consistent with individuals' ability to communicate.
- Some patients may understand spoken language, but not be able to speak. Others may speak fluently but not be able to accurately process auditory information, or may simply repeat words he/she has heard.
- Use of supporting or alternative communication
  - picture-based systems, text-based systems, sign language, or other signs or behaviors, is helpful. These devices may be stand-alone or exist as programs on tablets, smartphones, or paper notes.

Sensory Guidance

- See the child in a quiet room if possible.
- Use natural light or dim fluorescent lighting if appropriate.
- Encourage only one person to talk at a time.

Sensory Guidance

- Warn the patient before touching him/her.
- Avoid unnecessarily touching (for example, to express concern).
- Advise patient and/or supporters to bring objects to regulate sensory stimuli if needed
  - headphones
  - sunglasses
  - sensory toys

Autism Sensory Simulation

- https://www.youtube.com/watch?v=Lr4_dOorquQ

Patient Response

- Eye contact may be lacking, especially in distressing situations.
- Extra time to process information may be required.
- **Never assume a non-verbal person does not understand what is being said!**

Patient Response

- Expect YOU to understand what they are thinking.
- Stimming (pacing, hand flapping, fidgeting or rocking)
  - Do not assume the patient is inattentive or distracted
  - Are often stimming to cope with distress.
- Often invade personal space.

Adult Considerations

- Under the Americans with Disabilities Act, nurses must accommodate the specific needs of patients with ASD.
- Nurses should use individualized strategies to address limitations of patients with ASD that may contribute to barriers to healthcare. Persons with ASD struggling with social communications may find it difficult to request special accommodations. The Autism Healthcare Accommodations Tool (available at http://www.autismandhealth.org) may help patients with ASD create personalized accommodation reports for nurses and other healthcare professionals.
- Proactive responses to accommodation requests can save time and resources, improve therapeutic relationships, facilitate effective healthcare and help improve health outcomes of patients with ASD.

The Power of Pairing

- Pairing before demands are placed.
- "Pairing" is a common term that ABA professionals often use to describe the process of building or maintaining rapport with a client. Therapy often begins with intentional and thorough pairing, where its ALL about what the client loves or enjoys and making that available to them on a non-contingent basis (for FREE). The therapeutic relationship should start off with low demand, and high reward.
- Specify the reinforcer in the medical record.
- Note anything the child with ASD finds aversive.

A-B-C's of Behavior

- Think of behavior in terms of "why" it's occurring as opposed to "what" the behavior is.
- Every behavior has an antecedent and a consequence. These particular variables maintain those behaviors. A-B-C
- All behavior serves a function.
- While there are four possible functions of behavior, many behaviors in medical appointments are escape motivated.

Challenging Behavior

- Most medical exams and procedures are seen by patients as "demands" and are under conditions that are unusual or unfamiliar. This "tips the scale" in the direction of escape.
- Antecedent strategies increase the likelihood that patients will comply with the "demands" of the exam or procedure and refrain from problem behavior to attempt escape.
- Use behavior specific praise.

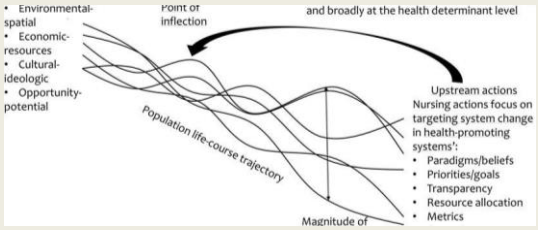
Pathologic Behaviors

- **Pathologic behaviors are:**
  - More difficult to overcome when allowed to persist
  - May eclipse more promising behaviors
  - Potential giftedness is less likely to be identified and refined with delayed or no behavioral interruption

Family Support

- "Tell me a little bit about your child…"
- "What are your biggest concerns?"
- Awareness of the grieving process
  - Tears are common….
- Importance of parent training
- Focus on opportunities during prognosis discussions.
- Explore appropraite action and avoid negative predictions.

Thinking Upstream



Multidiscipline Community Resources

- **Options and resources available at 3 years old…**
  - Speech Therapy
  - Play Therapy
  - Occupational Therapy
  - Nutritional Services
  - Applied Behavior Analysis
  - ECI non-profits
  - HeadStart
  - Special Education (ARDs, 504s)
  - Accommodations for standardized testing

Appropriate Action

The CDC directs concerned parents to their child's HCP first

If the HCP is concerned, or if the parent is still concerned, a referral to a specialist who can complete an in-depth evaluation and make a diagnosis should be placed. These credentialed professionals include:

- ✓ Developmental Pediatricians
- ✓ Child Neurologists
- ✓ Child Psychologists or Psychiatrists

Child Find Evaluation

Simultaneously, parents should be directed to the State's public early childhood system to request a free evaluation. This call does not require a HCP referral or a medical diagnosis.

- ❑ For children under 3 years of age, contact the local early intervention system.
- ❑ For children 3 years or older, contact the local public school system.

Unsure who to contact? Call the Early Childhood Technical Assistance Center (ECTA) at 919-962-2001 or visit: http://ectacenter.org/contact/619coord.asp

Looking Ahead

Nursing pioneer, Dr. Loretta Ford (co-founder of the Nurse Practitioner role) recently stated, "The art of nursing, perhaps more than the science, offers vulnerable groups something they need most: HOPE. The use of our presence with all its holistic emotional intelligence, caring, compassion and competence tells people that they are valuable and valued, unique, and worthy fellow human beings…

Looking Ahead

"Transformations can occur if vulnerable individuals are encouraged to find, focus and harness their strengths. As nurses, we can help them become invigorated, energized and emboldened to determine their future for themselves in health and in life" (email communication, April 2017).

One interaction at a time, nurses can successfully advocate for individuals with ASD.

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